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A Narrative Review of Patient and Family Engagement: The "Foundation" of the Medical Home

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Abstract

Background—Patient and family engagement (PFE) is vital to the spirit of the medical home. This article reflects the efforts of an expert consensus panel, the Patient and Family Engagement Workgroup as part of the Society of General Internal Medicine's 2013 Research Conference.

Objective—To review extant literature on PFE in pediatric and adult medicine and quality improvement, highlight emerging best practices and models, suggest questions for future research, and provide references to tools and resources to facilitate implementation of PFE strategies.

Methods—We conducted a narrative review of relevant articles published from 2000–2015. Additional information was retrieved from personal contact with experts and recommended sources from workgroup members.

Results—Despite the theoretical importance of PFE and policy recommendations that PFE occur at all levels across the health care system, evidence of effectiveness is limited, particularly for quality improvement. There is some evidence that PFE is effective, mostly related to engagement in the care of individual patients, but the evidence is mixed and few studies have assessed the effect of PFE on health outcomes. Measurement issues and the lack of a single comprehensive conceptual model pose challenges to progress in this field. Recommendations for future research and a list of practical tools and resources to facilitate PFE are provided.

Conclusion—Although PFE appeals to patients, families, providers, and policy-makers, research is needed to assess outcomes beyond satisfaction, address implementation barriers, and support

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engagement in practice redesign and quality improvement. Partnering with patients and families has great potential to support high quality health care and optimize outcomes.

Keywords

patient- and family-centered care; medical home; patient and family engagement; practice transformation; quality

Introduction

Patient and family engagement (PFE) in care is essential for optimal health outcomes and is a key component of the Patient-Centered Medical Home (PCMH) model. The Joint Principles of the PCMH[1] state that a PCMH should provide:

- A care planning process driven by partnerships between physicians, patients, and the patient's family.
- Active participation of patients in decision-making.
- Utilization of information technology to support optimal patient care, performance measurement, patient education, and enhanced communication.
- Active participation of patients and families in quality improvement at the practice level.[1]

As PCMH demonstration projects were developed and tested, concern and criticism surfaced that PCMHs were not sufficiently "patient-centered" or inclusive of patient and family perspectives.[2]

While the phrase "patient and family engagement" is often shortened to "patient engagement," we believe it is imperative to be explicit and consistent in the inclusion of the word "family." Families play a key role in promoting health and wellness, managing chronic and complex conditions, and assisting with transitions and ongoing care for patients of all ages. We need systems in place in primary and specialty care practices, and across the entire healthcare continuum that encourage family involvement in appropriate facets of patient care to the extent patients desire. Maintaining a broad definition of family as *"*two or more persons related in any way- biologically, legally, or emotionally," [3] is critical to ensuring that patients' choices about who will participate in their care are respected.

There are many definitions and conceptualizations of PFE (Table 1).[4–8] These definitions, while differing slightly, all articulate the importance of:

- Partnerships among patients, family members, and health care providers at multiple levels;
- Partnerships that are exemplified by specific behaviors, organizational policies and principles
- Patients and family members as essential members of the health care team;
- Partnerships for improving health, quality, safety, and delivery of healthcare

The importance of family engagement in care and decision-making has been a hallmark of pediatric care for thirty years.[9] In pediatrics, *patient* and *family* engagement are often conceptually "linked" because children are generally not considered autonomous decision-makers. Therefore, we will discuss PFE together as one entity in this manuscript. Conversely, in adult medicine, engagement is more nuanced. For adults with severe cognitive impairment or dementia, the conceptualization of engagement is similar to pediatrics because these adults *require* family participation in their care and decision-making. However, in functionally independent adults (e.g., those who do not need significant assistance with their activities of daily living) and those without severe cognitive impairment, patient engagement is conceptually distinct from family engagement and the tacit assumption is that family "engagement" is optional and may be unnecessary. Therefore, for this review, we present literature on family engagement separate from patient engagement.

In the following sections, we review key literature demonstrating the effectiveness of PFE in several areas, highlight emerging best practices and models for PFE, suggest questions for future research, and provide references to tools and resources to facilitate implementation of PFE strategies.

Methods

Patient and Family Engagement Workgroup

This article reflects the efforts of the Patient and Family Engagement Workgroup as part of the Society of General Internal Medicine's PCMH Research Conference II in May 2013.[10] The workgroup was comprised of a multidisciplinary expert panel of health care providers, health services researchers, and leaders from prominent community organizations dedicated to partnering with patients and families in health care at all levels. The workgroup met monthly over the year preceding the conference and reviewed evidence around PCMH and PFE. At the conference, the workgroup presented its findings to conference attendees, identified gaps and areas for growth, and discussed the policy-relevant research agenda for PFE. The group has continued to meet via conference calls to complete this manuscript.

Approach to the Literature

This article is not a systematic review, but rather a narrative or literature review[11] informed by existing systematic reviews relevant to the topic and the diverse perspectives of researchers, clinicians, and leaders of organizations with expertise in the field. We limited our search to empirical research which evaluated associations between patient and/or family engagement on outcomes or interventions to enhance patient and/or family engagement. We excluded commentaries, editorials, and articles using qualitative methods. We also excluded articles which examined associations between patient activation and outcomes or that focused on interventions to enhance patient activation without engaging patients or families in the design, implementation, or evaluation.

We conducted a preliminary literature search using Pubmed to identify articles related to PFE published between 2000 and 2015. Search terms included "patient and family

engagement," "patient engagement" OR "patient activation," "patient engagement" OR "patient activation" AND "quality," "medical home" AND "quality," "professional-family relations" AND "engagement," "professional-family relations" AND "companions," "professional-family relations" AND "family-centered care," "patient-centered care," "physician-patient relations" AND "quality" AND "participation," and "physician-patient relations" AND "engagement." Additional articles were found by reviewing reference lists, from the American Academy of Pediatrics[12] and Family Voices[13] websites, personal contact with experts, and recommended sources from workgroup members.

Results

We identified 14 relevant systematic reviews[14–27] and other primary publications related to PFE in direct care of individuals and quality improvement (QI).

Engagement in the Direct Clinical Care of Individuals

PFE in direct care can influence communication and information sharing, self-care, decision making, and safety. [14] The evidence we cite below highlights some of these potential avenues for engagement.

PFE in Pediatrics—At least one study in pediatrics has demonstrated that pediatric physicians are more patient-centered in their communication behaviors (e.g. provided more information) when they interacted with parents who were more engaged during the encounter (as manifested by asking questions, expressing preferences and concerns)[28]

A systematic review of 24 studies (including 7 randomized controlled trials [RCT]) analyzed evidence for family-centered care (FCC), conceptualized as family-provider partnership, for children and youth with special health care needs or similar populations. The review found that FCC is positively associated with several outcomes, including: efficient use of services, better health status (e.g., psychological functioning, quality of life, symptom severity), satisfaction with communication, systems of care, family functioning, and family impact/cost (e.g., parents missed work days). There was little evidence of effects of FCC on transition to adulthood and cost. [23]

Family engagement in care can also improve safety. A study by Benjamin and colleagues video-taped family-centered rounds in 150 hospitalized children. Their findings suggested that family-initiated communication about medication topics resulted in appropriate changes to the children's medications that altered treatment and was important for safety, adherence, and satisfaction.[29]

Most of the research on FCC in pediatrics has focused on the hospital setting. [23]: However, the National Center for Medical Home Implementation developed a comprehensive monograph including relevant research, tools to support partnership, and examples of best practices of such partnerships from 17 pediatric practices across the country.[30] The monograph describes strategies for partnering with families as reported by practices, including offering peer and family support; providing information and education

through written materials, programs, and events; ensuring culturally competent services; and offering opportunities for families to participate as partners for improvement.

The benefits of PFE during clinical rounds, where medical trainees present to attending physicians, has also been explored. A systemic review of 17 studies (15 in pediatric populations) sought to assess whether family presence during rounds, compared with non-inclusion of family members, leads to positive outcomes and increased satisfaction based on the perspectives of patients, parents, families, and health care providers.[21] The review noted benefits including increased feelings of inclusion and sense of teamwork, enhanced communication, better understanding of care plans, enhanced decision making, and greater satisfaction.[21] However, concerns relate to confidentiality and privacy, potential negative impact on trainee teaching (family presence leading to limited discussions or less teaching), and potential for increased family confusion/anxiety (feeling rushed to make decisions) were also noted.[21] Although FCR give patients and families opportunities to collaborate in care and planning, it does not guarantee that this participation occurs. Further education and research are needed to address barriers and improve family-centeredness.

Patient Engagement in Adult Care—Active participation of patients in their own care and decision-making is associated with positive results, including: higher quality, fewer errors, more positive views of the health care system, improved patient confidence- both in their ability to manage and control their own health conditions and also in the ability of the health system to deliver effective care.[26,31,32]

A growing literature has examined potential benefits of engaging patients in decision-making through the use of decision aids.[22,33,34] However, studies designed to evaluate decision aids often do not measure patient participation in decision-making during the medical encounter and their impact on clinically relevant outcomes.[35] Clayman and colleagues recently published a systematic review to assess the extent to which patient participation in decision making within medical encounters was associated with patient outcomes.[15] They identified 116 articles (11 of used RCT designs). The concluded that very few RCTs have included measures of both participation in decision making and at least one health outcome and attempted to relate the two. In addition, there was little consistency in the measurement of these variables, and results were mixed. Nearly half of the RCTs and most of the non-randomized studies reported an association between patient participation and at least one positive outcome.

Communication is an essential component of patient-provider relationships and the quality of communication is a useful lens for understanding the extent to which patients are engaged in their care. Studies have documented that patients' level of engagement has a reciprocal effect on physicians.[36–39] Specifically, physicians engage in more patient-centered communication[36] and provide more information[37] when interacting with high (versus low) participation patients (those who ask questions, provide information)

Interventions to enhance PFE in direct clinical care—Various interventions have been tested to enhance PFE. The classification model of patient engagement methods by Grande and colleagues provides is a useful tool for evaluating the feasibility of several

intervention approaches in real-world clinical settings.[40] Griffin and colleagues conducted the first systematic review of RCTs of interventions to alter the interaction between patients and providers and assess their effectiveness for improving patients' health and well-being.[27] The review found 35 relevant trials. Only one study linked the intervention through process to outcome measures. Moreover, health outcomes were measured objectively in only 6 of the 35 trials and only 4 of the trials with health outcomes met predefined quality criteria. The interventions significantly altered the process of interactions in the majority of the trials, with positive effects on health outcomes achieving statistical significance in 44% of the trials. The authors concluded that there are few rigorous trials of well-specified interventions to inform best practices.

A systematic review by Prey and colleagues of 17 studies (3 were RCTs) evaluated the use of health information technology to increase patient engagement in the inpatient setting.[19] The interventions were grouped into the following categories: entertainment (e.g., virtual reality/games), generic health information delivery (e.g., videos), patient-specific information delivery, advanced communication tools (e.g., video conferencing), and personalized decision support. This review highlighted research on PFE within the inpatient setting is nascent and the quality of the evidence-based is sparse. Only 2 studies in this review measured clinical outcomes (i.e. smoking cessation and length of stay), suggesting an area of investigation for future studies.

Adams and colleagues tested, in an RCT, whether use of an interactive voice response system, the Personal Health Partner (PHP) integrated with the EHR could improve the quality of pediatric primary care visits.[41] Parents of children aged 4 months to 11 years called the PHP before routine visits and their responses were used to provide tailored counseling and goal setting before the upcoming visit. Data were then transferred to the EHR for review during visits. Intervention parents were significantly more likely to report discussing important issues such as depression and prescription medication use and being better prepared for visits. Moreover, all of the clinicians reported that the PHP improved the quality of their care.

Other strategies have been evaluated in systematic reviews, including consumer e-health tools (e.g., secure e-mail messaging between patients and providers),[42,43] mobile phone messaging,[44,45] interactive applications for self-management of health,[46–49] and telephone communication.[50] Although some of these strategies do facilitate interaction between patients and providers, they may not necessary involve true "partnership" unless the exchange is bi-directional or patients and/or families are involved in the design, implementation, or evaluation.

Personal health records and online portals have also been used to foster PFE in care. The "Blue Button" feature of online patient portal home pages provided by public and private organizations such as the Department of Veterans Affairs (VA) allows patients to access certain parts of their electronic health record and share it with others. In a survey of over 18,000 participants from the VA, the majority of Blue Button users reported that it helped them understand their health history; 21% of users with a non-VA provider reported sharing

their VA health information, and 87% reported that the non-VA provider found the information somewhat or very helpful.[51]

One hundred primary care physicians and >20,000 of their patients participated in the OpenNotes study, which allowed patients access to clinic notes written by their physicians.[52] Most patients who responded to the post-intervention survey reported an increased sense of control, greater understanding of their medical issues, improved recall of their plans for care, better preparation for future visits, and better medication adherence. Twenty to forty two percent of patients reported sharing the notes with family members. Physicians frequently commented that OpenNotes strengthened relationships with some of their patients and that participation did not adversely affect their work loads.

Family Engagement in Adult Care—A growing literature supports the beneficial role families play in the health care of adults. Accompaniment to medical visits and participation in medical visit communication are specific ways families demonstrate engagement that is particularly relevant to the PCMH. Studies report family member accompaniment occurs in approximately 20% to 60% of health care encounters.[24,53] Family member presence during visits has been shown to facilitate patient-physician communication and self-management behaviors.[53–62] Companions behaviors include recording physician instructions, facilitating doctor understanding by relaying information regarding patients' medical history or needs, asking questions, explaining physicians' instructions, and supporting medical decision making.[53,56,57,62] In some studies, family accompaniment has been associated with greater patient satisfaction with the counseling and care they receive from health care providers.

A systematic review of 52 studies examined the influence of triadic (adult patient-family member-physician) communication within medical visits on decision-making.[20] There were generally no significant differences in communication behaviors in dyadic (patient and physician only) versus triadic visits. The review also found that patients and physicians perceive family members as helpful to the encounter; however, family members report feeling ignored by physicians and physicians report a lack of training in techniques to communicate with family members. It is possible that optimizing family engagement in routine medical visits may present a viable strategy for improving chronic care and ameliorating health disparities for certain patients. However, few studies have examine the effect of accompaniment and level of family engagement in medical visit communication on health outcomes and health care utilization.[24,20] Few interventions have specifically targeted family members who accompany patients to medical visits to assess the impact of family engagement on processes and outcomes of care.[63]

Patient and Family Engagement in QI in Practices

PFE in practice improvement can involve participating in QI activities, patient/family advisory councils, practice redesign, or providing feedback through surveys or focus groups. There is little empiric research on PFE in QI, despite calls for such research.[64] However, initial descriptive studies are emerging. Four programs utilizing PFE in QI efforts are presented in the 2010 AHRQ paper on engaging patients and families in the medical home.[14] The authors note that there is very little evidence about the impact of PFE in

practice improvement activities on outcomes for the practices, clinicians, staff, or patients. The lack of evidence of effectiveness in turn limits adoption and implementation of such an approach. The most successful models for PFE in QI efforts come from large practice settings or smaller practices linked to a collaborative network, so there remains a question about the feasibility of implementing PFE strategies into routine practice for smaller settings.

The American Academy of Family Practice's Collaborative Care Research Network and the National Committee of Quality Assurance conducted a study of patient involvement in QI at the practice level in 112 NCQA-recognized PCMHs.[64] Using a web-based survey tool and follow-up interviews, they determined only 32% of practices formally involved patients in QI teams or advisory groups. The authors concluded that achieving true patient- and family-centeredness will require a cultural shift in how patients are thought of as partners in, rather than solely as recipients of, care.[64]

Table 2 highlights several emerging PFE best practices and models.[65–68]

Limitations—The methodology of a narrative review strengths and limitations. While providing a current overview of a topic for those seeking a broad perspective in a readable format, there is a risk of selection bias due to a lack of rigid inclusion/exclusion criteria and weighting of studies, and author subjectivity in analyses and conclusions. However, co-authoring this manuscript with leaders of national organizations dedicated to partnering with patients and families and training health care providers and health care system leaders in PFE provides a unique perspective that strengthens the manuscript. We mitigate the potential for bias by describing our search strategy and including systematic reviews. We acknowledge that not all relevant studies, models, or best practices are included in this manuscript, nor does this manuscript discuss in detail all areas where PFE may occur. However, information pertinent to areas not discussed in this paper can be found elsewhere.[14]

Discussion—Based on our review of the literature and our unique multidisciplinary perspectives, we have reached several key conclusions. First, there is great interest in and rhetoric directed towards the importance of partnering with patients and families across various levels to improve the effectiveness, efficiency, and safety of health care. [69] Second, while there is some evidence that PFE is effective, mostly related to engagement in the care of individual patients, the evidence is mixed. There have been relatively few empiric studies examining the effectiveness of PFE in QI, safety, and policy change. Third, there is little practical guidance for how to facilitate PFE.[70,71]

Several critical factors slow progress in this area. First, we lack a single comprehensive theory-driven conceptual model that explicates the mediating pathways and outcomes of PFE,[4] even though frameworks exist for understanding engagement in specific areas.[72] Such a model would allow researchers and implementation scientists the opportunity to explicitly test their hypothesized causal models. Second, very few validated measures exist to define or quantify the outcomes of patient and/or family engagement across the various levels.[73–75] Existing measures conflate engagement with other constructs which have validated

measures, such as the patient activation measure,[76] patient empowerment measures,[77] and patient experience measures.[75] More work is needed in measure development if we are to track and monitor progress of engagement and assess what works and how it works over time. Finally, there is no MESH term for "patient and/or family engagement." Terms used to assess these constructs are often used without consistency. This highlights Coulter's conclusion that "…much is known about effectiveness of PFE strategies and best practices to support it, but available evidence in ambulatory practices is limited because the literature is widely dispersed among various disciplines and journals."[78] Finally, much remains to be learned about best practices for implementing PFE strategies at the various levels across the health care system.

Although many interesting and promising PFE models exist, further exploration is warranted to advance this research. Table 3 provides a list of the most pressing research questions/issues that we feel would advance the field of PFE in health and health care. These questions are generally consistent with research needs published in the 2010 AHRQ review of PFE in the medical home,[14] and other sources. Table 4 provides a list of recommendations and resources to facilitate PFE across various levels of care.[79–92]

Conclusion

Despite a general consensus within the medical community of the importance of partnering with patients and families,[3,14,53] more work needs to be done to operationalize these partnerships and evaluate the effectiveness and impact of strategies designed to enhance engagement. A systematic approach to integrating PFE strategies into health care delivery is needed.[78] Engaging patients and families as active partners in their health and health care should not be a privilege afforded to a select group, but a right for all patients.

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References

1. American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, American Osteopathic Association. [Accessed January 23, 2016] Joint Principles of the Patient-Centered Medical Home. Feb. 2007 Available at: http://www.aafp.org/dam/AAFP/documents/practice_management/pcmh/initiatives/PCMHJoint.pdf
2. Aysola J, Bitton A, Zaslavsky AM, et al. Quality and equity of primary care with PCMH. Results from a national survey. Med Care. 2013; 51(1):68–77. [PubMed: 23047125]
3. [Accessed January 23, 2016] Institute for Family-Centered Care web site. Frequently asked questions. Dec 29. 2010 Available at: http://www.familycenteredcare.org/faq.html

4. Carman K, Dardess P, Maurer M, et al. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. Health Affairs. 2013; 32(2): 223–231. [PubMed: 23381514]
5. American Hospital Association. Engaging health care users: A framework for healthy individuals and communities. Chicago, IL: American Hospital Association; Jan. 2013 2012 Committee on Research, Benjamin K. Chu and John G. O'Brien, co-chairs
6. Minniti, M.; Abraham, M. Essential allies—Patient, resident, and family advisors: A guide for staff liaisons. Bethesda, MD: Institute for Patient- and Family-Centered Care; 2013.
7. Maurer, M.; Dardess, P.; Carman, KL., et al. Guide to patient and family engagement: Environmental scan report. Rockville, MD: Agency for Healthcare Research and Quality; May. 2012 (Prepared by American Institutes for Research under contract HHSA 290-200-600019). AHRQ Publication No. 12-0042-EFAvailable at http://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/final-reports/ptfamilyscan/ptfamilyscan.pdf [Accessed January 23, 2016]
8. Brown SM, Rozenblum R. Defining Patient and Family Engagement in the ICU. Am J Respir Crit Care Med. 2015; 191(3):358–60. [PubMed: 25635496]
9. American Academy of Pediatrics Committee on Hospital Care and the Institute for Patient and Family Centered Care. Patient and family centered care - the pediatrician's role. Pediatrics. 2012; 129(2):394–404. [PubMed: 22291118]
10. Society of General Internal Medicine. [Accessed January 23, 2016] Patient-centered medical home. Available at: http://www.sgim.org/communities/clinical-practice/patient-centered-medical-home
11. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Info Libr J. 2009; 26(2):91–108. [PubMed: 19490148]
12. [Accessed on January 23, 2016] American Academy of Pediatrics Website. Available at https://www.aap.org/en-us/Pages/Default.aspx
13. [Accessed on January 23, 2016] Family Voices Website. Available at http://www.familyvoices.org/
14. Scholle, SH.; Torda, P.; Peikes, D., et al. Engaging patients and families in the medical home. Rockville, MD: Agency for Healthcare Research and Quality; Jun. 2010 AHRQ Publication No 10-0083-EF
15. Clayman ML, Bylund CL, Chewning B, et al. The impact of patient participation in health decisions within medical encounters: A systematic review. Med Decis Making. 2015 Nov 19. pii: 0272989X15613530. Epub ahead of print.
16. Berger Z, Flickinger TE, Pfoh E, et al. Promoting engagement by patients and families to reduce adverse events in acute care settings: a systematic review. BMJ Qual Saf. 2014; :1–8. DOI: 10.1136/bmjqs-2012-001769
17. Bolen SD, Chandar A, Falck-Ytter C. Effectiveness and safety of patient activation interventions for adults with type 2 diabetes: systematic review, meta-analysis, and meta-regression. J Gen Intern Med. 2014; 29(8):1166–76. [PubMed: 24733301]
18. Durand MA, Carpenter L, Hayley D. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. PLos One. 2014; 9(4):e94670. [PubMed: 24736389]
19. Prey JE, Woollen J, Wilcox L, et al. Patient engagement in the inpatient setting: A systematic review. J Am Med Infor Assoc. 2014; 21(4):742–50.
20. Laidsaar-Powell RC, Butow PN, Bu S, et al. Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. Patient Educ Couns. 2013; 91(1):3–13. [PubMed: 23332193]
21. Cypress BS. Family presence on rounds: A systemic review of literature. Dimens Crit Care Nurs. 2012; 31(1):53–64. [PubMed: 22156815]
22. Flynn D, Knoedler MA, Hess EP, et al. Engaging patients in health care decisions in the emergency department through shared decision-making: A systematic review. Acad Emerg Med. 2012; 19(8): 959–967. [PubMed: 22853804]
23. Kuhlthau KA, Bloom S, Van Cleave J, et al. Evidence for family-centered care for children with special health care needs: A systematic review. Acad Pediatr. 2011; 11(2):136–43. [PubMed: 21396616]

24. Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review. Soc Sci Med. 2011; 72(6):823–31. [PubMed: 21353358]
25. Kinnersley P, Edwards A, Hood K, et al. Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. BMJ. 2008; 337:a485. [PubMed: 18632672]
26. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ. 2007; 335(7609):24–27. [PubMed: 17615222]
27. Griffin SJ, Kinmonth AL, Veltman MW, et al. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners. Ann Fam Med. 2004; 2(6):595–608. [PubMed: 15576546]
28. Cegala DJ, Chisolm DJ, Nwometh BS. Further examination of the impact of patient participation on communication style. Patient Education and Counseling. 2012; 89:25–30. [PubMed: 22560252]
29. Benjamin JM, Cox ED, Trapskin PJ, et al. Family-initiated dialogue about medications during family-centered rounds. Pediatrics. 2015; 135(1):94–101. [PubMed: 25511116]
30. Malouin, RA. American Academy of Pediatrics. Elk Grove Village, IL: National Center for Medical Home Implementation; 2013. Positioning the family and patient at the center: A guide to family and patient partnership in the medical home.
31. Osborn R, Squires D. International perspectives on patient engagement: Results from the 2011 commonwealth fund survey. J of Ambul Care Manage. 2012; 35(2):118–28. [PubMed: 22415285]
32. Schoen, C.; Osborn, R. [Accessed January 23, 2016] The Commonwealth Fund 2004 international health policy survey of primary care in five countries. Chartpack. Available at http://www.commonwealthfund.org/~/media/files/surveys/2004/2004-commonwealth-fund-international-health-policy-survey-of-adults-experiences-with-primary-care/2004_survey_charts-pdf.pdf
33. Stacey D, Legare F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014 Jan 28.1:CD001431. Available at http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001431.pub4/pdf/standard. [PubMed: 24470076]
34. Stacey D, Samant R, Bennett C. Decision making in oncology: a review of patient decision aids to support patient participation. CA Cancer J Clin. 2008; 58(5):293–304. [PubMed: 18755939]
35. Kryworuchko J, Stacey D, Bennett C, et al. Appraisal of primary outcome measures used in trials of patient decision support. Patient Educ Couns. 2008; 73(3):497–503. [PubMed: 18701235]
36. Cunningham P. Patient engagement during medical visits and smoking cessation. JAMA Intern Med. 2014; 174(8):1291–1298. [PubMed: 24911033]
37. Cegala DJ, Post DM. The impact of patients' participation on physicians' patient- centered communication. Patient Education and Counseling. 2009; 77:202–208. [PubMed: 19395225]
38. Cegala DJ, Street RL Jr, Clinch CR. The Impact of patient participation on physicians information provision during primary care medical interview. Health Commun. 2007; 21:177–185. [PubMed: 17523863]
39. Street RL, Gordon H, Haidet P. Physicians' communication and perceptions of patients: is it how they look, how, they talk, or is it just the doctor. Soc Sci Med. 2007; 65(3):586–598. [PubMed: 17462801]
40. Grande SW, Faber MJ, Durand MA, et al. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. Patient Educ Couns. 2014; 95(2):281–7. [PubMed: 24582473]
41. Adams WG, Barrett D, Phillips J, et al. Automated conversation system before pediatric primary care visits: a randomized trial. Pediatrics. 2014; 134(3):1–9. Available at http://pediatrics.aappublications.org/content/pediatrics/early/2014/07/29/peds.2013-3759.full.pdf. [PubMed: 24918219]
42. Ricciardi L, Mostashari F, Murphy J, et al. A national action plan to support consumer engagement via e-health. Health Aff. 2013; 32(2):376–84.
43. Finkelstein, J.; Knight, A.; Marinopoulos, S., et al. Enabling patient-centered care through health information technology. Rockville, MD: Agency for Healthcare Research and Quality; Jun. 2012 Evidence Report/Technology Assessment No. 206. (Prepared by Johns Hopkins University

Evidence-based Practice Center under Contract No. 290-2007-10061-I.) AHRQ Publication No. 12-E005-EFAvailable at www.effectivehealthcare.ahrq.gov/reports/final.cfm [Accessed January 23, 2016]

44. Gurol-Urganci I, De Jongh T, Vodopivec-Jamsek V, et al. Mobile phone messaging reminders for attendance at healthcare appointments. Cochrane Database Syst Rev. 2013; 12:CD007458. [PubMed: 24310741]
45. Vodopivec-Jamsek V, De Jongh T, Gurol-Urganci I, et al. Mobile phone messaging for preventive health care. Cochrane Database Syst Rev. 2012; 12:12, CD007457.
46. Marcano-Belisario JS, Greenfield G, Huckvale K, et al. Smartphone and tablet self- management apps for asthma. Cochrane Database Syst Rev. 2013; 11:CD010013. [PubMed: 24282112]
47. Pal K, Eastwood SV, Michie S, et al. Computer-based diabetes self-management interventions for adults with type 2 diabetes mellitus. Cochrane Database Syst Rev. 2013; 3:CD008776. [PubMed: 23543567]
48. Wieland LS, Falzon L, Sciamanna CN, et al. Interactive computer-based interventions for weight loss or weight maintenance in overweight or obese people. Cochrane Database Syst Rev. 2012; 8:CD007675. [PubMed: 22895964]
49. Murray E, Burns J, See Tai S, et al. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev. 2005 Oct 19.(4):CD004274. [PubMed: 16235356]
50. Cash-Gibson L, Felix LM, Minorikawa N, et al. Automated telephone communication systems for preventive healthcare and management of long-term conditions. Cochrane Database Rev. 2012
51. Turvey C, Klein D, Fix G, et al. Blue Button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal. J Am Med Inform Assoc. 2014; 21(4):657–63. [PubMed: 24740865]
52. Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. Annals of Internal Medicine. 2012; 157(7):461–70. [PubMed: 23027317]
53. Wolff JL, Roter DL. Hidden in plain sight: medical visit companions as a resource for vulnerable older adults. Arch Intern Med. 2008; 168(13):1409–1415. [PubMed: 18625921]
54. Cene CW, Haymore LB, Lin FC, et al. Family member accompaniment to routine visits is associated with better self-care in heart failure patients. Chronic Illn. 2015; 11(1):21–32. [PubMed: 24740555]
55. Wolff JL. An exploration of patient and family engagement in routine primary care visits. Health Expect. 2015; 18(2):188–98. [PubMed: 23107095]
56. Rosland AM, Piette JD, Choi H, et al. Family and friend participation in primary care visits of patients with diabetes or heart failure: Patient and physician determinants and experiences. Med Care. 2011; 49(1):37–45. [PubMed: 21102357]
57. Jansen J, van Wheert JC, Wijngaards-de Meij L, et al. The role of companions in aiding older cancer patients to recall medical information. Psychooncology. 2010; 19(2):170–179. [PubMed: 19319855]
58. Rosland, AM. Sharing the Care: The role of family in chronic illness. Oakland, CA: California Healthcare Foundation; 2009.
59. Sayers SL, White T, Zubritsky C, et al. Family involvement in the care of healthy medical outpatients. Family Pract. 2006; 23(3):317–324.
60. Clayman ML, Roter D, Wissow LS, et al. Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. Soc Sci Med. 2005; 60(7): 1583–1591. [PubMed: 15652689]
61. Ishikawa H, Roter DL, Yamazaki Y, et al. Physician-elderly patient-companion communication and roles of companions in Japanese geriatric encounters. Soc Sci Med. 2005; 60(10):2307–2320. [PubMed: 15748678]
62. Shields CG, Epstein RM, Fiscella K, et al. Influence of accompanied encounters on patient-centeredness with older patients. J Am Board of Fam Pract. 2005; 18(5):344–354. [PubMed: 16148244]

63. Wolff JL. A tool to strengthen older patient-companion partnership in primary care: Results from a pilot study. J Am Geriatr Soc. 2014; 62(2):312–329. [PubMed: 24417565]
64. Han E, Scholle SH, Morton S, et al. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. Health Affairs. 2013; 32(2):368–375. [PubMed: 23381530]
65. California HealthCare Federation. [Accessed January 23, 2016] Team Up for Health. 2011. Available at: http://www.teamupforhealth.org/
66. The Commonwealth Fund. [Accessed January 23, 2016] Rhode Island's Pediatric Practice Enhancement Project: Parents Helping Parents and Practitioners. 2010. Available at: http://www.commonwealthfund.org/~/media/Files/Publications/Case%20Study/2010/Jan/1361_SilowCarroll_Rhode_Island_PPEP_case_study.pdf
67. Robert Wood Johnson Foundation. [Accessed January 23, 2016] Aligning forces for quality: Oregon's patients and families as leaders program. Patient and family as leaders in health care. n.d. Available at: http://www.qcorp.org/sites/qcorp/files/PAFL%20Summary%20Document.pdf
68. Narayan, A.; Baron-Lee, J.; Esquivel, M., et al. Family feedback always assessment tool for pediatric patients. MedEdPORTAL Publications; 2015. Available at: https://www.mededportal.org/publication/10105 [Accessed January 23, 2016]
69. Institute of Medicine. Best care at lower cost: The path to continuously learning health care in America. Washington, D.C: The National Academies Press; 2012. Available at: http://www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx [Accessed January 23, 2016]
70. Kemper C, Blackburn C, Doyle JA, et al. Engaging patients and families in system-level improvement: a safety imperative. Nurs Adm Q. 2013; 37(3):203–15. [PubMed: 23744466]
71. Longtin Y, Hugo S, Leape LL, et al. Patient participation: current knowledge and applicability to patient safety. Mayo Clin Proc. 2010; 85(1):53–62. [PubMed: 20042562]
72. Holzmueller CG, Wu AW, Pronovost PJ. A framework for encouraging patient engagement in medical decision-making. J Patient Saf. 2012; 8(4):161–4. [PubMed: 22892584]
73. Barr PJ, Thompson R, Walsh T, et al. The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process. J Med Internet Res. 2014; 16(1):e2. [PubMed: 24389354]
74. Sebastian RA, Ramos MM, Stumbo S, et al. Measuring youth health engagement: development of the youth engagement with health services survey. J Adolesc Health. 2014; 55(3):334–40. [PubMed: 24709299]
75. Dyer N, Sorra JS, Smith SA, et al. Psychometric Properties of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Clinician and Group Adult Visit Survey. Medical Care. 2012; 50(Suppl):S28–S34. [PubMed: 23064274]
76. Hibbard JH, Stockard J, Mahoney ER, et al. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Serv Res J. 2004; 39(4):1005–26.
77. Barr PJ, Scholl I, Bravo P, et al. Assessment of patient empowerment - a systematic review of measures. PLOS One. 2015; 10(5):e0126553. [PubMed: 25970618]
78. Coulter A. Patient engagement - what works? J Ambul Care Manage. 2012; 35(2):80–89. [PubMed: 22415281]
79. [Accessed January 23, 2016] The CAHPS Ambulatory Care Improvement Guide: Practical Strategies for Improving Patient Experience. Available at https://cahps.ahrq.gov/quality-improvement/improvement-guide/improvement-guide.html
80. Frampton, S.; Guastello, S.; Brady, C., et al. [Accessed January 23, 2016] Patient-centered care improvement guide. 2009. Available at planetree.org/wp-content/uploads/2012/01/Patient-Centered-Care-Improvement-Guide-10-28-09-Final.pdf
81. [Accessed January 23, 2016] Institute for Patient and Family-Centered Care Website. Available at http://www.ipfcc.org/tools/downloads-tools.html
82. Partnership for Clear Healthcare Communication at the National Patient Safety Foundation. [Accessed January 23, 2016] Available at http://www.npsf.org/default.asp?page=askme3

83. [Accessed January 23, 2016] The Joint Commission's "Speak Up" Patient Safety Program. Available at http://www.jointcommission.org/speakup.aspx
84. Pelletier LR, Stichler JF. Action brief: Patient engagement and activation: A health reform imperative and improvement opportunity for nursing. Nurs Outlook. 2013; 61:51–54. [PubMed: 23527404]
85. [Accessed January 23, 2016] AHRQ Patient and Family Engagement Module. Available at http://www.ahrq.gov/professionals/education/curriculum-tools/cusptoolkit/modules/patfamilyengagement/index.html
86. Center for Advancing Health. [Accessed January 23, 2016] Be a prepared patient. Available at www.cfah.org/prepared-patient
87. The Joint Commission. [Accessed January 23, 2016] Advancing effective communication, cultural competence, and patient-and family-centered care: a roadmap for hospitals. 2010. Available at www.jointcommission.org/assets/1/6/ARoadmapforhospitalsfinalversion727.pdf
88. US Department of Health and Human Services. [Accessed January 23, 2016] Health care information and management systems society's patient engagement framework. Available at http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28305
89. Robert Wood Johnson Foundation. [Accessed January 23, 2016] Engaging patients in improving ambulatory care. 2013. Available at http://www.rwjf.org/en/library/research/2013/03/engaging-patients-in-improving-ambulatory-care.html
90. Hibbard J. The dos and don'ts of patient engagement in busy office practices. J Ambul Care Manage. 2012; 35(2):129–132. [PubMed: 22415286]
91. Carman, KL.; Dardess, P.; Maurer, ME., et al. A roadmap for patient and family engagement in healthcare practice and research. Gordon and Betty Moore Foundation; Palo Alto, CA: Sep. 2014 (Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation, Dominick Frosch, Project Officer and Fellow; Susan Baade, Program Officer.)Available at http://patientfamilyengagement.org/#sthash.UvS7WsfG.dpuf [Accessed January 23, 2016]
92. American Academy of Pediatrics. [Accessed January 23, 2016] Medical home resources. Available at https://www.aap.org/en-us/professional-resources/practice-support/medicalhome/Pages/home.aspx

Table 1

Various Definitions and Conceptualizations of Patient and Family Engagement

Source	Definition/Conceptualization
Carman et. Al, *Patient and family engagement: A framework for understanding the elements and developing interventions and policies*[4]	Patient and family engagement is a process in which "patients, families, [and] their representatives [are] working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care."
American Hospital Association (AHA) report, *Engaging Health Care Users: A Framework for Healthy Individuals and Communities*[5]	Health care user engagement is "a set of behaviors by health professionals, a set of organizational policies and procedures," and "a set of individual and collective mindsets and cultural philosophies that foster both the inclusion of patients and family members as active members of the health care team and encourage collaborative partnerships with patients and families, providers and communities." The AHA framework includes engagement at individual, health care team, organizational, and community levels.
Minniti and Abraham, *Essential allies— Patient, resident, and family advisors: A guide for staff liaisons*, Institute for Patient- and Family-Centered Care[6]	Collaborative patient and family engagement is a strategy for achieving a patient- and family- centered system of care and patient and family engagement occurs at four levels: • In the clinical encounter…patient and family engagement in direct care, care planning, and decision-making; • At the practice or organizational level… patient and family engagement in quality improvement and health care redesign; • At the community level…bringing together community resources with health care organizations, patients, and families; and • At policy levels…locally, regionally, and nationally.
Guide to Patient and Family Engagement: Environmental Scan Report[7] (p. 9)	A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations… the desired goals of patient and family engagement include improving the quality and safety of health care in a hospital setting.
Betty and Gordon Moore Foundation, Libretto Consortium PFE Integration Group[8]	Patient and family engagement in the Intensive Care Unit is an active partnership between health professionals and patients and families working at every level of the healthcare system to improve health and the quality, safety, and delivery of healthcare. Arenas for such engagement include but are not limited to participation in direct care, communication of patient values and goals, and transformation of care processes to promote and protect individual respect and dignity. PFE comprises five core concepts: Collaboration, Respect and Dignity, Activation and Participation, Information Sharing, and Decision Making

Table 2

Emerging Best Practices and Models for Patient and Family Engagement

Team Up for Health[65]

- **Area(s) of PFE:** Direct Care, Practice Redesign, QI
- **Goals/Objectives:** A 3-year initiative designed to advance the practice of self- management support in five safety net clinics and one primary care/multispecialty group practice in California.
- **Intervention/Methods:** This project provided practices with technical assistance to further PFE at three levels—individual care, QI, and in expanding use of community resources. Each organization was supported in partnering with patients and families.
- **Results:** Developed tools and strategies, in partnership with patient and family advisors, to engage, empower, and educate patients and their families. Examples of one tool developed is "Making the most out of your visit," an agenda setting form.

The Pediatric Practice Enhancement Project (PPEP)[66]

- **Area(s) of PFE:** Practice Redesign, QI
- **Goals/Objectives:** Accomplish the Healthy People 2010's Maternal & Child Health objective to increase the proportion of children and youth with special health care needs who have access to a medical home.
- **Interventions/Methods:** Rhode Island Department of Health contracted with the Rhode Island Parent Information Network to train and places parent consultants (called Family Resource Specialists) into pediatric primary and specialty care practices to help families with children and youth with special health care needs.
- **Results:** The PPEP model resulted in increased use of outpatient primary and preventive care and decreased use of more costly inpatient stays. In addition, families served by PPEP Family Resource Specialists reported having a better understanding and satisfaction with the health care delivery system, felt more empowered, and were more knowledgeable of the community resources available to them.

Patients and Families as Leaders: Transforming Patient and Family Engagement in Oregon[67]

- **Area(s) of PFE:** Direct Care, Practice Redesign, QI **Goals/Objectives:** Trains patients and physicians to work together at multiple decision-making levels within the health care system. This initiative brought together four primary care clinics and one Medicaid health plan to develop patient and family advisory councils.
- **Interventions/Methods:** They develop a Medical Advisory Council at CareOregon (a care plan supporting Medicare and Medicaid recipients). Sites worked collaboratively to develop a guide to help CareOregon members prepare for care visits by identifying goals and expectations for clinic visits.
- **Results:** The Member Advisory Council helped improve internal operations for CareOregon, expand dental coverage for members and expand their work into the broader community. They enhanced the partnerships at the direct care level through the collaboratively developed guide, "Better Together." Their engagement and partnership influenced legislation in the development of the Community Advisory Councils (CACs) that serve to inform the Coordinating Care Organizations (CCO) throughout Oregon (Oregon's version of Accountable Care Organizations). As a result, 51% of CAC membership must be individuals who are receiving Medicaid services or who are family members of Medicaid recipients.

Residency Education Initiative Work Group (REIWG)[68]

- **Area(s) of PFE:** Direct Care, Practice Redesign, QI
- **Goals/Objectives:** The REIWG was convened under the auspices of the National Center for Medical Home Implementation and the American Academy of Pediatrics to better understand the perspectives of current residency programs to inform future development of a national medical home residency education curriculum. The primary objective of this workgroup was to identify pediatric training needs related to the medical home for all children, including children and youth with special health care needs, care coordination, and family-centered care.
- **Interventions/Methods:** Workgroup members include representatives from: American Academy of Pediatrics, Academic Pediatric Association, Association of Pediatric Program Directors, residency program directors, residents, family members, and medical home content experts. This group: 1) conducted a needs assessment of pediatric residency program directors regarding medical home training for pediatric residents and 2) results of the needs assessment informed an online curriculum for pediatric residency training with strategies and core competencies for the medical home. The REIWG received funding from the Picker Institute to pilot a program on residents' ability to elicit family feedback and shared decision making during clinical encounters.
- **Result:** The workgroup demonstrated that evidence of formal medical home curriculum experiences in residency education is limited despite the fact that pediatric residency programs want to incorporate medical home education into their curricula. The results also demonstrated feasibility and favorable associations for fostering shared decision making and working with families in residency education.

Table 3

Future Research Needs/Questions to Advance the field of Patient and Family Engagement

Proposed Research Questions
Patient and Family Engagement in Direct Care
What education and support strategies are most effective in encouraging and supporting patients and families to engage effectively in their own health care and how do these strategies compare to one another?
How does a patient's access to their clinical information impact health outcomes, health care utilization, and patient safety?
What key concepts should be included in standardized measures to assess patient and family engagement in primary care?
How do we best measure (e.g. validate) the impact of patient and/or family engagement at the individual level on access to care, utilization, health outcomes, patient and family satisfaction, and patient safety?
How feasible is it for primary care practices to implement patient and family engagement strategies beyond research projects?
How do we measure the impact of patient and/or family engagement on a practice, including staff and clinician satisfaction, staffing, cost efficiency, and time?
Education for Physicians and Staff to Encourage and Support Patient and Family Engagement in Individual Care
What education and support strategies are most effective in encouraging and supporting physicians and staff to partner effectively with patients and families?
In what ways can health information technology support the development and implementation of patient and family engagement strategies/ tools; for whom (i.e. which patients) and under what conditions are these strategies most likely to be successful?
How do we best train physicians in the additional competencies required (e.g., communicating with patients and their families during clinic visits) to effectively engage family members in ambulatory visits for adult patients?
Patient and Family Engagement in Practice Redesign and Quality Improvement
What infrastructure and key behaviors or actions on the part of the health care organization are needed to foster and sustain involvement of patient and family advisors in primary care transformation, QI, safety, or other efforts to improve care?
What is the best method to provide training and support to patients and families so that they can effectively participate as advisors in quality improvement initiatives and primary care redesign efforts?
What are the training needs of health care professionals, patients and families to better facilitate effective partnerships in quality improvement and practice redesign?
What are the added benefits and costs of engaging patients and families in QI and primary care redesign efforts?
Patient and Family Engagement in Research
How can we best engage individual patient and family advisors and patient- and family-led organizations in the development of measurement tools, the design of measurement protocols, the implementation of relevant research studies and the interpretation/ dissemination of results?
What are the best methods for preparing patient and family advisors and patient- and family- led organizations to partner in primary care medical home research?

Table 4

Recommendations and Resources to Facilitate Patient and Family Engagement across Various Levels of Care

Recommendations	
1. Ask patients and families what "engagement" means to them and what aspect of engagement matters most to them.	
2. Explicitly invite and welcome family presence at medical visits, if the patient prefers, and provide patients and families with evidence-based strategies that have been shown to enhance patient-provider communication.	
3. Include patient and family advisors in design and implementation of research, interpretation, and dissemination of research findings, after proper training.	
4. Train future members of the health care workforce (physicians, nurses, social workers, medical assistants, administrative staff) in principles of PFE and set the expectation (e.g., include it as part of formal job descriptions) that excellence in PFE is a requirement of the job.	
5. Assess the level of engagement of patient and families in shared decision making, care planning, transition planning, all aspects of community partnering, and patient /family care experience and continually engage in QI around patient/family engagement to give feedback on clinical experience and ideas to providers and clinical practices.	
6. To encourage patient engagement in decision making, consider asking the following 2 questions: a) What are you worried about?; b) What are your goals following treatment?[77]	
Resources	
1	AHRQ Quality Improvement Guide[79] (https://cahps.ahrq.gov/quality-improvement/improvement-guide/improvement-guide.html) – offers information on how to use patient experience data in quality improvement.
2	Planetree and Picker Institute's Patient-Centered Care Improvement Guide[80] – offers strategies to engage patients in quality improvement activities.
3	Institute for Patient and Family-Centered Care[81] (http://www.ipfcc.org/tools/downloads-tools.html) – provides numerous resources and tools related to collaborating with patients and families.
4	National Center for Medical Home Implementation's Positioning the Family and Patient at the Center Guide[30] - a comprehensive monograph including relevant research, tools to support partnership, and examples of best practices of such partnerships from pediatric practices across the country
5	National Patient Safety Foundation Partnership for Clear Healthcare Communication's Ask Me 3 TM[82] (http://www.npsf.org/default.asp?page=askme3)- an educational program designed to improve patient-provider communication and patient engagement by guiding patients to ask questions meant to give the care provider essential information used in diagnostic decision making.
6	The Joint Commission's "Speak Up" Patient Safety Program[83] (http://www.jointcommission.org/speakup.aspx) - provides free online access to infographics, animated videos, brochures, and posters designed to increase patient safety through patient engagement.
7	American Academy of Nursing Action Brief on Patient Engagement[84] – offers recommendations to enhance engagement in practice, research, education, and policy.
8	Guide to Patient and Family Engagement: Environmental Scan Report[7] – defines engagement and promotes PFE in hospital settings.
9	AHRQ Patient and Family Engagement Module[85] – focuses on PFE in the hospital setting
10	American Hospital Association's framework on Engaging Health Care Users[5] – offers best practices of PFE strategies for health care teams in hospitals.
11	Center for Advancing Health's framework on Engagement Behavior[86] – suggests 43 engagement behaviors for patients.
12	The Joint Commission's Roadmap for Hospitals[87] – a guide for engaging patients in hospitals
13	US Department of Health and Human Services/Health Care Information and Management Systems Society's Patient Engagement Framework[88] – promotes the use of eHealth tools in the development of PFE strategies.
14	Robert Wood Johnson Foundation PFE Toolkit[89] – presents PFE strategies of primary care practices
15	Kemper's "Engaging Patients and Families in System-Level Improvement"[70] – provides a framework to assess patient and family engagement and practical steps and strategies aimed to improve engagement at the organizational/system level.
16	Hibbard's "The Dos and Don'ts of Patient Engagement in Busy Office Practices"[90] – provides a summary of strategies providers can use to facilitate patient engagement and strategies that should be avoided.
17	American Academy of Pediatrics Residency Education Work Group has developed Medical Home Modules for Pediatric Residency Education including one on patient and family engagement available for use https://www.aap.org/en-us/professional-resources/practice-support/medicalhome/Pages/home.aspx[91]

Recommendations	
18	Carman's "A Roadmap for Patient and Family Engagement in Healthcare Practice and Research"[92] (http://patientfamilyengagement.org/#sthash.UvS7WsfG.dpuf) provides a wealth of knowledge and evidence related to PFE as well as opportunities to improve engagement.